DOCUMENT RESUME

ED 250 861 EC 170 896

AUTHOR Hobbs, Nicholas; And Others

TITLE Chronically Ill Children in America: Background and Recommendations.

INSTITUTION Vanderbilt Univ., Nashville, Tenn. Center for the Study of Families and Children.

SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.; Office of Special Education and Rehabilitative Services (ED), Washington, DC.; Robert Wood Johnson Foundation, New Brunswick, N.J.
PUB DATE Apr 83
NOTE 60p.
PUB TYPE Reports - Research/Technical (143)

EDRS PRICE MF01/PC03 Plus Postage.
DESCRIPTORS Costs; *Diseases; Family Problems; Health Services; *Policy Formation; *Public Policy; *Special Health Problems

ABSTRACT

The report examines chronic illness in children and considers issues and recommendations for change in public policies and programs affecting chronically ill children and their families. The background chapter notes the significance of the problem, reviews 11 diseases that are representative of the severe chronic illnesses of childhood: juvenile onset diabetes, muscular dystrophy, cystic fibrosis, spina bifida, sickle cell anemia, congenital heart disease, chronic kidney disease, hemophilia, leukemia, cleft palate, and severe asthma. These conditions serve as "marker" diseases, i.e., they have characteristics that make them representative of the total range of such illnesses. Definitions of chronicity and severity are also considered in the background section. Section 2 focuses on the organization, costs, and financing of health care services for chronically ill children. A brief section on public policy principles concludes that policies should be designed to help families carry out their responsibilities to nurture their children and encourage their development. The fourth section advocates the establishment of a regional program that emphasizes comprehensiveness of service, coordination, continuity, and communication. The concluding section examines issues and recommends changes in the health care system regarding organization and financing of services, schools, research, and training of service providers. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
☑ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

ED250861

Chronically Ill Children in America: Background and Recommendations

Nicholas Hobbs, Ph.D.*
James M. Perrin, M.D., Principal Investigator
Henry T. Ireys, Ph.D., Co-Principal Investigator
Linda Christie Moynihan
May W. Shayne, A.C.S.W.

April, 1983

Center for the Study of Families and Children
Vanderbilt Institute for Public Policy Studies
1208 18th Avenue, South
Nashville, TN 37212
615-322-8505

This document is a preliminary report of the project, "Public Policies Affecting Chronically Ill Children and Their Families," funded by grants from: the Division of Maternal and Child Health, U.S. Department of Health and Human Services; the Office of Special Education and Rehabilitative Services, U.S. Department of Education; and the Robert Wood Johnson Foundation. The final report, The Constant Shadow: Childhood Chronic Illness in America, will be published by Jossey-Bass, Inc., Publishers. San Francisco, CA, in 1984.

*deceased

EC170896

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY
James M. Perrin
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

Chronically Ill Children in America:
Background and Recommendations

Contents

I. Background..... 1
Significance of the Problem..... 1
Chronically Ill Children as a Class..... 2
Advances in Health Care and Public Programs..... 5
Chronicity and Severity: Definitions..... 6
Epidemiology and Prevention..... 8

II. The Organization, Costs and Financing of Health Services for Chronically Ill Children.....11
Organization of Services.....11
Costs of Care.....13
Financing of Care.....15

III. Principles for Public Policy.....25

IV. A National Regionalized Program for Chronically Ill Children and Their Families.....27

V. Issues and Recommendations for Change in Existing Policies and Programs.....34
Organization of Services.....34
Financing of Services.....37
Schools.....46
Research.....50
Training of Providers.....54

Chronically Ill Children in America:
Background and Recommendation

I. Background

Significance of the Problem

Children who suffer from severe, chronic illness are a neglected group in our society. Their suffering, the heavy burdens they and their families bear, the human resources lost to us all are matters largely unknown to the general public. Chronically ill children live out their lives in a twilight zone of public understanding. As a consequence, our nation, ordinarily attentive to problems of children and families, has lagged in its response to the urgent needs of children with chronic illnesses. The Vanderbilt project attempts to make available to caring citizens and to the shapers and makers of policy the information they need to address effectively one of the nation's least known but most urgent health problems.

Eleven diseases representative of the severe chronic illnesses of childhood have been examined closely: juvenile-onset diabetes, muscular dystrophy, cystic fibrosis, spina bifida, sickle cell anemia, congenital heart disease, chronic kidney disease, hemophilia, leukemia, cleft palate, and severe asthma. The eleven conditions serve as "marker" diseases, that is, they have characteristics that make them representative of the total range of such illnesses. Considered separately, each disease is relatively rare and occurs in a small percentage of the childhood population. Taken all together, however, perhaps a million children are severely involved and another 9 million have less severe chronic illnesses. In considering a

million children with severe chronic illnesses, we also refer indirectly to at least three million family members burdened with caring responsibilities. affected by anxiety and sometimes by guilt, strapped by unpredicted expenses and possibly economic ruin, and facing an uncertain future that often includes the premature death of the child. Thus the emphasis on families in our work. Our concern is mainly with the more extreme end of the distribution of chronically ill children, with less than 1.5 percent of the childhood population, whose problems are so special that the health system falters and extraordinary efforts are required to make it work even moderately well. The project is primarily concerned with public policies, that is, with policies of governments (federal, state, and local) and of large organizations such as professional associations, industries that employ many people and insurance companies. Our concern is with formal policies, whatever the source, that affect numbers of chronically ill children and their families.

Chronically Ill Children as a Class

Chronically ill children can be considered as a class for the purpose of organizing services and allocating resources. The special needs of severely and chronically ill children and their families cannot efficiently and effectively be met simply by extending to this group policies that are efficient for children with routine illnesses, with acute or even fatal illnesses, with stable handicapping conditions (such as mental retardation), or with mild chronic illnesses such as allergies, transient asthma, and minor gastrointestinal problems.

For several reasons, there has been a tendency to regard each chronic illness separately. Among the reasons are the physiological diversity of

the diseases, the variation in the expected length of life, and the diversity of treatments. A result is that each disease has its corps of specialists, its affiliation with specialty clinical centers, its advocacy group, and its champions in the Congress and state legislatures, each competing with the other for scarce funds.

From a policy perspective, however, the diseases have more in common with each other than they do with other illnesses of childhood. We emphasize that not always, but in general, severe chronic illnesses of childhood share the following characteristics. Most of the diseases are costly to treat. Direct medical treatment costs, including hospitalization, may run high, and long-term care may be costly, too: blood and blood products, insulin, syringes, special diets, drugs, orthopedic devices, transportation, long distance telephone calls, oxygen, control of environmental temperature, glasses, hearing aids, special schooling, and nursing care provided professionally or by family members and friends. Most of the diseases require care over an extended period of time; thus costs mount steadily. In acute diseases, costs may be high but for a short period. By contrast, severe chronic illnesses have both periods of brief high costs plus the continuing costs, never low, for a long period of time. The costs of these diseases may be so great that a family can be made bankrupt; insurance may be impossible to obtain; and employment opportunities for parents and family members may be severely curtailed.

Most of the diseases require only intermittent medical care, at the time of diagnosis and the establishment of a treatment regime, at subsequent routine checks, and in periods of crisis. Thus the daily burden of care, day after day, week after week, year after year, falls on the family. Our society is organized to take care of many kinds of handicapped people,

young and old, but not the chronically ill child. Formal resources for the daily out-of-hospital care of such children are almost nonexistent.

Many of the diseases entail a slow degeneration and premature death. The future course of all the diseases is highly unpredictable. The uncertainty thus generated creates great psychological problems for the child and his family.

Most of the diseases are accompanied by pain and discomfort, sometimes beyond appreciation by the normal individual. Furthermore, most of the diseases require treatments that in themselves are arduous, often painful, sometimes embarrassing, to the point where the afflicted family may wonder whether a prolonged life is worth it after all.

The integration of medical care, not normally a problem, takes on serious proportions when severe and chronic illness of children is involved. The integration of primary, secondary, and tertiary care is essentially nonexistent. Primary care physicians uncommonly see a child with each of the marker diseases. There may be difficulties in early identification and referral, in allocation of responsibility for continuing care and for coordination among health providers and schools.

As a further link among these disparate physiological states, policy itself creates ties among the chronically ill. By policy, some states provide treatment for sickle cell disease, some do not; some provide treatment for the complications of diabetes, others do not, thus requiring parents who are fortunate enough to be informed to move to communities where there are tertiary care centers or to states that have policies providing assistance to children with particular diseases. And our nation as a whole simply does not provide, at a cost manageable by most parents, the resources it takes to treat a child with a severe chronic illness. Perhaps there is no stronger bond among children with severe and chronic illnesses,

and their families as well, than the absence of an examined policy pertaining to them.

Advances in Health Care and Public Programs

Dramatic progress has been made in preventing some diseases, in bringing others under at least a measure of control, and in actually curing some children with certain diseases that were formerly incapacitating or lethal. Much of the progress has resulted from research leading to new knowledge and from technological developments leading to improved treatment techniques. Progress has also been made in shaping public and private health care programs so that afflicted children and their families can benefit from scientific and clinical advances. As a consequence, the prospects today for the child seriously ill with a chronic disease or disorder are considerably better than they were in years past.

Examples of achievements in acquiring knowledge and then in putting that knowledge to work through enlightened public policies are: the discovery in 1922 of insulin, enabling the control of juvenile diabetes; research at mid-century leading almost to the elimination of three major disabling conditions of childhood -- poliomyelitis, tuberculosis, and rheumatic heart disease; progress within the last two decades in treating renal disease through transplants and dialysis; development of surgical techniques to alleviate some heart conditions and neural tube defects; advances in the treatment of leukemia with chemical and radiation therapies; treatment of hemophilia with the development of cryoprecipitate; development of means to detect various fetal anomalies in utero making early intervention possible; and genetic typing and counseling which can improve family planning and reduce the incidence of some chronic illnesses of childhood.

The scientific and clinical achievements have been paralleled in many instances by the development of social structures. They include: the establishment of the Crippled Children's Service in 1935; mandatory immunization against poliomyelitis and other childhood illnesses including public expenditures to insure availability; reimbursement for health care for children through Medicaid, Supplemental Security Income Disabled Children's Program, and Medicare (for ESRD treatment); the Developmental Disabilities Program, extended in the late 1970's to include children with severe and chronic illnesses; Public Law 94-142, the Education for All Handicapped Children's Act, which includes chronically ill children in its definition of handicapped children; basic biomedical research on severe chronic childhood illnesses through the National Institutes of Health; and registers to determine correlations between environmental hazards and birth defects and chronic illnesses.

While much has been accomplished, there is much to be done in the acquisition of knowledge and its application through organizational and financial mechanisms. The successes of the past foretell the very real achievements that lie ahead in the alleviation of the adverse effects of severe chronic childhood illnesses.

Chronicity and Severity: Definitions

A chronic illness is one that lasts for a substantial period of time or that has sequelae that are debilitating for a long period of time. The common diseases of childhood provide a convenient reference point for defining chronicity. Most illnesses of childhood are self-limiting and run their course in a period of hours, day, or weeks. Even the acute and serious illnesses of childhood, with proper treatment, require a month or

so for complete convalescence. By contrast, most of the severe, chronic illnesses of childhood persist for a few to a number of years after onset and have a variable course, some improving, some remaining stable and some becoming progressively worse. A general definition of chronic illness is a condition which interferes with daily functioning for greater than three months in a year, causes hospitalization of more than one month in a year, or (at time of diagnosis) is likely to do so.

While the meaning of chronicity can be rather readily agreed upon, defining severity is a much more complex matter. There are simply no good reference points that find ready acceptance. For some of the chronic illnesses here considered, there is a strong inclination among physicians to refuse to assess severity at all, at least not on a physiological basis. For example, either a child has juvenile-onset diabetes or he hasn't, and how well he may be getting along at any particular time is more a reflection of the quality of care and compliance rather than of severity.

For the purposes of this inquiry into public policies affecting chronically ill children and their families, we advance five criteria to assess the severity of impact of an illness, in addition to available criteria of physiologic severity.

1. The illness places a large financial burden on the family. For the diseases considered here, out-of-pocket medical cost may exceed ten percent of family income after taxes;

2. The illness significantly restricts the child's physical development. Many of the children here considered will be well below normal height and weight as the result of the illness;

3. The illness significantly impairs the ability of the child to engage in accustomed and expected activities;

4. The illness contributes significantly to emotional problems for the child as expressed in maladaptive coping strategies;

5. The illness contributes significantly to the disruption of family life as evidenced, for example, in increased marital friction and sibling behavior disorders.

Defining chronicity and severity on a generic basis to serve public policy purposes is hazardous. The definitions we propose emphasize the social impacts of the diseases in an effort to broaden the conventional disease-oriented definitions. Perhaps most important in considering severity is the recognition that these criteria identify very different groups of children and families. Children with the most physically debilitating arthritis, for example, may have far less emotional problems from the illness than have children with milder disease.

The Epidemiology of Chronic Childhood Illness

The dramatic medical advances of the past few decades have meant that many children who would have died previously of their chronic illnesses now survive to young adulthood. For almost all childhood illnesses, there is little evidence of changing incidence - that is, the number of new cases appearing in a population of stable size. Furthermore, there is evidence that most potential gains in longevity have already occurred. Thus, the number of children with chronic illnesses is presently mainly dependent on the number of new children in the population; and with a stable (rather than growing) child population, the numbers of children with chronic illnesses will also be stable.

About 10-15% of the childhood population has a chronic illness. Among chronically ill children, about 10% (or 1-2% of the total childhood

population) have severe chronic illnesses. With the marked decline in morbidity and mortality from infectious diseases among children, and with the increasing survival of children with severe chronic illnesses, the 1-2% have become a much larger part of pediatric practice. Among adults, chronic illnesses tend to be few in number and mainly fairly common: arthritis, hypertension, diabetes, coronary artery diseases, etc. In contrast, the chronic illnesses of children are mainly relatively rare, and there is a tremendous variety of conditions.

The etiologies of chronic childhood illness vary greatly. Most known etiologies incorporate both genetic and environmental factors, with different prospects for prevention and intervention. Methods of intervention include: avoidance of procreation by parents at risk for having a child with chronic illness; detection in utero of a chronic disorder followed by termination of pregnancy or by medical treatment of the fetus; treatment of genetic diseases through genetic engineering; screening of newborns to detect chronic illnesses before they are expressed symptomatically, and followed by early treatment; and control of environmental causes -- toxic chemicals, drugs, tobacco, viruses. All of the strategies for intervention have associated technical uncertainties and raise perplexing ethical dilemmas.

Tremendous advances in understanding the mechanisms of diseases and the possibilities of prevention have occurred in the last decade. There remain nevertheless real barriers, some ethical and some technological, to preventing many or most chronic childhood illnesses. A key problem is that there is a large number of specific conditions, and prevention approaches usually develop on a disease-by-disease basis.

Thus, chances appear high that children with severe chronic illnesses will remain part of the nation's population for the foreseeable future. A balanced appraisal would encourage basic research on prevention, but would recognize the need for continued address to the amelioration of the secondary physiological, social and psychological effects of chronic childhood illnesses, which will remain a part of our contemporary experience.

II. The Organization, Costs and Financing of Health Services for Chronically Ill Children

Organization of Services

Diversity and fragmentation characterize the organization of services for chronically ill children. There is tremendous variation in the care families receive, based on such characteristics as the interest of the specialists in an academic center, the urban or rural nature of the community, and the organization of governmental services, especially Crippled Children's Services. In some areas, a broad variety of family support services are available; in others, available services are limited to medical and surgical interventions.

Families often identify great frustration from the fragmentation of services. They may see one or more specialists a distance from their home; among the specialists, there may be disagreement about plans for the child. Especially for children with multiple handicaps, arranging to be Monday morning in the cardiology clinic, Tuesday afternoon in the neurology clinic, and on Thursdays in the orthopedist's office becomes itself a major management problem.

The availability of needed medical and surgical services, notably for specialty care, has improved dramatically in the past fifteen or twenty years. Among primary care providers, there has also been a significant improvement in the distribution of general physicians and nurse practitioners in the past ten to twenty years such that far more small communities have adequate primary care services available.

Despite greater availability, access to adequate specialty medical services is a problem in some communities. Most chronic conditions of childhood are rare and thus community prediatricians and other primary

providers, despite the quality of their training, may have little recent experience with an unusual malignancy, severe renal disease, or hemophilia in their practice. Similarly, despite the quality of nursing staff, the hospital with just a few hundred deliveries per year will have very little experience with conditions which occur in perhaps 1 in 10,000 live births. Not only may identification be a complex issue, but referral may be a problem as well.

Access to non-medical services is highly variable. Some communities may have excellent, comprehensive programs for children with specific health problems, such as the comprehensive hemophilia centers in some areas. In other locales primary care providers offer coordination which assures the availability of a broad range of non-medical services to families of children with chronic illnesses. The emphasis on medical and surgical care, to the neglect of other services for families, can have a great impact on a child's development and functional abilities. As an example, a child undergoing corrective cardiovascular surgery needs attention not only to his medical and surgical care but also to his schooling. What can be done to diminish his falling behind his classmates; what plans should be made for his activity when he returns to school; are home-bound teachers appropriate for a period of time?

Such services can be provided in many ways. Yet the fundamental problem in providing many of them is the lack of reimbursement for the services. Genetic counseling, as an example, is often dependent upon federal research or service support, and with cyclical variations in the support, genetic services may come and go in a relatively brief period of time.

Costs of Care

For most children in the United States, health care costs are small. Average yearly health expenditures for children not living in institutions were only $286.07 in 1978. This average figure, however, disguises a distribution that is extraordinarily skewed. Most children incur minimal health care expenses; relatively few require care that costs an enormous amount. For example, only 5.4 percent of persons under 17, many of whom were chronically ill, were hospitalized one or more times in 1978, at an average cost of $1,920. The rest of the childhood population had no hospital expenditures at all. There are also many chronically ill children in the 2 percent of the nation's population that uses over 60 percent of all in-patient resources each year.

The typical pattern of a high-cost childhood chronic illness involves a series of out-patient treatments and hospitalizations over many years, together with routine daily home-care or self-care procedures. This pattern generates many obvious medical costs, for hospitals and physicians, medications, lab and X-ray services, and often for such services as physical therapy or social work. Many costs not easily categorized or assessed are also generated; these include transportation costs, extra telephone costs, costs associated with time lost from work or school (often referred to as lost opportunity costs), costs for special diets, and emotional costs associated with increased worry and stress within the family. For each illness the specific medical and social-emotional costs will differ, but for almost every family, both types of cost will be major factors in the financial picture.

Though chronically ill children represent a segment of society for which health care costs are disproportionately high, information available

on the costs and financing of services for these children. For example, no studies are available that enable comparisons across many illnesses and that also take account of the wide range of family needs related to the illness. Instead, most studies focus on specific illnesses and generally on medical services, excluding other services equally relevant to care but often delivered outside of medical settings.

In view of the absence of comprehensive, cross-diagnosis data, we can only conclude with certainty that costs of care, defined broadly, are high for this class of children. Three examples follow.

Spina Bifida. The birth of a child with spina bifida initiates a series of surgical procedures, rehabilitation efforts, and management strategies that will continue for the life of the child. Since many children with this disorder now live into their fourth decade, the total costs of care are likely to be enormous. The actual cost for any given child will depend on the site of lesion, the success of management efforts, preferences of the child's physicians and family, travel distance between the home and the site for the delivery of medical care, and a host of other factors. Variations in these factors produce a wide range of total costs across individuals.

Average medical costs (in the mid 1970's) from birth to age six were $13,000 for children with low lesions and $25,000 for children with high lesions. Average total costs of care (extending beyond strictly medical care) from birth to two years old was $70,000 (in 1980 dollars). The mean cost of care for the first three weeks of life for an infant born with spina bifida is $6,500.

Asthma. Compared to spina bifida, severe asthma is far more frequent and average costs are likely to be much less. One study showed that costs

for 21 families with 35 cases of asthma ranged between $61 and $3,200 over a three year period. In 1980 dollars, this is a range of $130 to $6,000. As with many other chronic illnesses, the source of much of the variance in medical costs is related primarily to the number of attacks per year that require hospitalization. If attacks can be minimized through good preventive care and regular monitoring by the pediatrician or allergist, the yearly costs will be smaller. Asthma is also a chronic illness for which lost opportunity costs are high. Several studies indicate that asthma accounts for more absences from school than any other single medical disorder.

Hemophilia. Hemophilia is one of the few childhood chronic illnesses in which costs have decreased over the last decade. The decrease has resulted primarily from improvements in the isolation and storage of clotting factors, improvements that have decreased reliance on tertiary care settings by permitting prevention and treatment at home. Despite these improvements, care for children with hemophilia remains expensive and substantially variable from one child to another, with a yearly mean cost of medical care of $8,071 and a median of $5,000. Total yearly medical costs vary substantially from no cost for a child with a very mild case to $56,000 for a young adult with a very severe case.

Financing of Care

The system for financing health care in this country is a potpourri of federal programs, state programs, and private insurance arrangements. The complexity of the system is particularly frustrating for parents with a child whose existence is dependent both on specialized medical procedures and on general health services. While most chronically ill children have a large protion of their medical care supported by some third-party arrangement,

there remain large gaps in coverage. For some families these gaps can be financially ruinous. We present below a discussion of the six primary sources of payment for health care (broadly defined) of children with chronic illness: private insurance companies; disease-oriented voluntary associations; Medicaid; state Crippled Children Service programs (CCS); special state programs; and out-of-pocket monies.

Private Health Care Insurance. Approximately 75 percent of the nation's children are covered by some form of private insurance. Most children (68 percent of all children) receive benefits under group plans, usually covered as dependents of employed parents. These general figures might suggest that most of the nation's children are adequately protected. A closer look, however, reveals several major shortcomings of private health care insurance, particularly in relation to chronically ill children.

First, private health care insurance is actually medical care insurance. Private plans are designed to cover hospital and physician costs, some lab and drug costs, and a few additional services. They do not cover many costs that families with a chronically ill child will generate, including costs of transportation, home renovations, compensation for time lost from work by parents, custodial care, or counseling.

A second serious drawback of private health care insurance involves the various exclusions embedded in most plans. Exclusions can result from an unwise choice by a parent regarding the limits or breadth of coverage or from various types of refusal by the insurers.

Perhaps the most important limitation of private health care insurance is simply the fact that it does not cover many Americans; it especially does not cover children who have limitations in activity and who live in families whose income is below the poverty line. Of these children (numbering about

a million), only 17.5 percent are covered by private insurance. The rest are either uninsured or covered under public programs. Furthermore, the number of children, chronically ill included, who are not covered by private insurance tends to increase substantially during periods of high enemployment, when families lose coverage under group plans and cannot afford the costly premiums of an individual plan. For some chronically ill children not covered by private health insurance, other sources of support are available, though each of them also has limitations.

Medicaid. The largest health care financing program that involves children is the Medicaid program, also known as Title XIX of the Social Security Act. (Medicare involves a larger number of dollars but touches only a small group of children: those with end-stage renal disease.) Jointly funded by federal and state governments, Medicaid requires all states to pay for certain services for low income families and allows states to pay for any of an additional 27 services. Eligibility requirements, in many states, are tied to the nation's major welfare program, the Aid to Families with Dependent Children (AFDC) Program. In these states, to be eligible for Medicaid, a family must first be enrolled in the AFDC program.

Some states have elected the "medically needy" option, an important one for chronically ill children. Under this option, families with dependent children or with one absent, unemployed, or incapacitated parent can qualify for Medicaid even if the family income is above the Medicaid cut-off point, but only if the family's income falls below the cut-off point when medical expenses are subtracted. Even in states that offer this option, actual implementation has been spotty.

Many chronically ill and disabled children living in low income families are not eligible for Medicaid. Forty percent of all the nation's disabled

children in poverty are not eligible for Medicaid. Twenty-two states have Medicaid programs that cover at least half of the low income handicapped children; 27 state Medicaid programs do not cover even half of this population. If a low-income chronically ill or handicapped child is eligible for Medicaid, it is likely that the program will pay for only some of the services that he or she will need.

Crippled Children's Service (CCS). The CCS program started in 1935 and was the only major public source of support for the care of low-income chronically ill children until the early 1960's, when Medicaid and a variety of categorical programs began. The original legislation established federal grants for states that states would then match. CCS agencies, initially appointed by state governors, would administer and distribute these funds for the purpose of locating, diagnosing, and providing a range of services to "children who are crippled or who are suffering from conditions that lead to crippling." In August, 1981, Congress established the Maternal and Child Health Block Grant and in so doing removed all federal statutory requirements for a state CCS agency. In most states, CCS agencies continue to exist because of state legislation but they all have substantially less federal monies (although not necessarily less state monies). In these states, the CCS program still plays a major role in the care of chronically ill children. It sets and disseminates standards of care, provides for a fairly broad set of services, and covers children from a wide range of income levels. At its best, the CCS program represents an arena in which both the organization and the financing of care merge. It is the only broad-based child health program to have influence over both sides of the child health care coin.

The CCS programs have provided much care to many children with chronic illnesses. About $280 million dollars were spent by CCS agencies in 1979; of this amount, 31 percent ($86 million) were federal monies. CCS programs served about a million children in 1979, though state programs varied considerably in the number served expressed as a percentage of children in the state. Data from a recent survey show that in 1980, state CCS programs served 0.91 percent of the nation's children, compared to 0.33 percent in 1948.

Disease Oriented Voluntary Associations. Almost every childhood chronic illness has an associated advocacy group. The origin, scope and available resources of these organizations vary widely. For example, the Muscular Dystrophy Association spent $56.6 million in 1979; the Cystic Fibrosis Foundation spent $11.6 million in 1980; the Leukemia Society $3.8 million in 1980.

These organizations also allocate varying amounts of money to medical services, patient education and training. As a whole, they tend to pay for services that are not reimbursable within the usual system of care, such as special prostheses, recreational activities, or transportation. There is little specific information available regarding how many children are served or how much is spent per child by the voluntary foundations.

Perhaps the most important role that they play, however, is one of advocate. In the past they have supported state CCS programs, often persuading state legislatures to spare the CCS program. For this reason, these organizations may be crucial actors over the next few years, as state legislatures exercise the freedoms given to them by the Maternal and Child Health Block Grant. On the national level, they have often played a critical role in supporting Federal research expenditures in their areas of interest.

Out-of-pocket expenditures. Regardless of the type and extent of coverage that parents may have for their chronically ill child, out-of-pocket expenditures can be high and unpredictable. Families with a child with asthma spent an average of 14 percent of family income on medical costs. In a survey in 1980, the Cystic Fibrosis Foundation found that 20 percent of the respondents reported out-of-pocket costs greater than 30 percent of family income; more than half the respondents said that these expenses were greater than 10 percent of family income. A study of families with children with spina bifida revealed that the average out-of-pocket expenses were 12 percent of the family income. When income loss and non-medical costs were included, out-of-pocket expenses were 25 percent of family income.

Special state programs. Prior to the introduction of the Maternal and Child Health Block Grant, the federal government had a series of categorical grants to states for child health programs, several of which related directly to chronically ill children. The Hemophilia Treatment Center projects and the Genetic Disease programs are two examples. Although the monies involved in these programs tended to be small, they often provided important seed or ancillary money for state-initiated model programs. In 1980, state hemophilia centers, designed to provide comprehensive care to patients living in an identified region, spent almost $8 million. In fiscal year 1979, the federal government appropriated $11.7 million to the Genetic Disease Program.

These federal programs do not exist as independent programs any longer but there are many state programs, off-spring of the federal initiatives, that are continuing. In addition, several diseases have

associated state-initiated programs. There are, for example, cystic fibrosis programs operating in several states, developed usually from advocacy efforts spearheaded by local chapters of the Cystic Fibrosis Foundation. There are few data on any of these state-based categorical programs, or on the number of children and families that they serve. Yet, in some states they represent an important, albeit small, source of support for health care of chronically ill children.

Recent Initiatives. In addition to the sources of funding discussed above, there are several newer initiatives in the health care field that have potential for shaping the care of chronically ill children. Of these, the most important is the emergence of Health Maintenance Organizations (HMOs); we shall discuss them in some depth. Others are proposals for catastrophic health insurance and the development of a pro-competitive approach; because their future is more uncertain, we touch on them lightly.

HMOs provide coverage to about 5 percent of those persons who have private health care insurance, although the number of employees who have been joining HMOs, has been increasing steadily over the last decade at a rate of 12 percent per year. Thus, HMOs do not now cover many individuals but may cover substantially more if the present rate of growth continues through the coming decade.

An HMO is essentially a special type of insurance arrangement between enrollees and a group of health care providers. Under this type of arrangement, the enrollee pays a fixed fee per month (usually matched by the employer) in return for a range of outpatient and inpatient services provided as needed through the HMO and to associated hospitals. The HMO has its own providers whose salaries are paid essentially from total

enrollment fees less any costs that the HMO must pay to cover services that its own labs or providers cannot deliver. If an enrollee, for example, needs specialty care not available through the HMO, the patient is referred to the appropriate provider and the HMO then pays for the cost of this service, within limits defined in the enrollee's plan. Unlike fee-for-service arrangements, the underlying incentives of HMOs push toward services that avoid high-cost technology. Thus, they emphasize preventive services and outpatient or home-based care.

HMOs include both prepaid group practices, which typically provide hospital and physician services using salaried staff members, and individual practice associations, typically sponsored by local medical societies, which contract with physicians for the delivery of services to enrollees. As with private health care plans, families are likely to have access to HMOs (especially to prepaid group practices) only if they are members of an employee group. Thus, unless the head of a family with a chronically ill member is employed by an organization that offers an HMO option, the family is not likely to have access to an HMO. If they do, however, families that report having a chronically ill member (child or adult) are slightly more likely to enroll in an HMO than in a fee-for-service plan. They are likely to do so largely because prepaid plans cover a broader range of services, have lower and predictable out-of-pocket costs, and ensure access to care within or through one location. In comparison to fee-for-service arrangements, HMOs are more likely to cover office-based or home-based care; these are precisely the settings in which chronically ill children receive most of their care; in comparison to fee-for-service arrangements, HMO enrollees are likely to have lower

average out-of-pocket and premium costs and are at lower risk for large expenses.

Yet, HMOs are likely to discourage large enrollments of chronically ill children, primarily because such children will require more frequent services from the HMO as well as specialty services that must be provided outside of the HMO (and hence cost the HMO more). The HMOs thus present a mix of potential benefits and limitations.

In addition to the growth of HMOs, the past decade has seen a great deal of interest in protection for catastrophic health expenses. Four states (Connecticut, Maine, Minnesota and Rhode Island) have enacted catastrophic insurance requirements for insurers doing business in their states. Criticism of the catastrophic approach has come from many quarters. Most frequent is the criticism that insuring for high cost illness or procedures causes a reallocation of health care resources to categories of care that are already receiving a disproportionate share to the detriment of primary care services. Yet, catastrophic plans would ensure coverage of severe illnesses that depend extensively on high-cost technology. In this way, they could make a valuable contribution.

Zook, Moore and Zeckhauser observe that most proposals for catastrophic health insurance are based on misconceptions about the nature of catastrophic illness. They found that, contrary to popular understanding, high cost illness "is more often long-term and repetitive than short-term and acute," and that few proposals "contain incentives for providers to develop long-term care programs to reduce readmissions." Moreover, they argue, a benefit structure based on a one-year deductible is inequitable. Persons with chronic illness require a longer term benefit structure; for example, a child with certain congenital abnormalities

or ongoing disease might never qualify in a single year, but might require a series of treatments and hospital visits over an extended period of time. Clearly, families with chronically ill children require a benefit structure that limits out-of-pocket expenditures over a period longer than a single year.

Recently, policymakers have evidenced considerable interest in cost containment and, following the regulatory approaches of the 1970s, legislative attention has turned in the early 1980s to market strategies, often called competitive approaches, to reduce costs. Policymakers have advocated two competitive approaches, the first calling for an increase in cost sharing by the medical consumer (accomplished by providing insurance packages that are less rich or that require coinsurance) and the second calling for greater use of prepaid health plans. The important question for chronically ill children in the implementation of a competitive approach is what should be the minimum level of benefits in a federally qualified plan (a plan that qualifies for federal tax exemption). The question of minimum benefits is enormously important. Omission of needed services from the minimum would place families of chronically ill children at a considerable disadvantage if healthy families chose low cost plans with only minimal coverage and unhealthy families were left in high cost comprehensive benefit plans.

III. Principles for Public Policy

Policy concerning chronically ill children should address the gaps between the special needs of the children and their families and the characteristics of the health care system. From consideration of the policy issues encountered in the study, the project has identified certain basic principles which should underlie policy, regardless of specific organizational and program characteristics.

.Children with chronic illnesses and their families have special needs which merit attention, beyond that provided to the health needs of able-bodied children. Improvements in health services in general will improve the lot of chronically ill children, and policy development for chronic childhood illness should be integrated with other developments in national child health policy. Nonetheless, the special needs common to most children with chronic impairment will continue to need special attention in public policy.

.Families have the central role in caring for their own members and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development.

.Services should be distributed in an equitable and just fashion, specifically excluding from the distribution formula such nonfunctional characteristics as race, sex and socioeconomic class.

.Policy should ensure that a broad array of services is available to families with chronically ill children--beyond the usual medical-surgical or health services.

.Policy should encourage professional services of a highly ethical nature. Key elements include truth telling, confidentiality, maintenance

of dignity and respect for family preference, professionals' recognition of limits of their own effectiveness, and emphasis on collaboration.

.Chronically ill children should stay on task in school to the greatest degree possible. Schooling is the main occupation of young people, and the interference of illness and its treatment with educational activities should be diminished.

.The public commitment to sound basic research has resulted in tremendous advances in the health of chronically ill children. Policy should encourage the continuation and expansion not only of biological research, but also of psychological, biosocial and health services research related to chronic illness in childhood.

IV. A National Regionalized Program for Chronically Ill Children and Their Families

The complex special needs of families with chronically ill children will be best met through a regionalized system of care. The system of care should arise through a new national program, emphasizing coordinated regional efforts, providing services as close to a child's home as possible, and ensuring access to all children with chronic handicapping conditions. Services provided in each region should be characterized by comprehensiveness, continuity of care, and excellent communication among providers and between providers and families.

Scope of services. To achieve comprehensiveness, each region needs to define a broad basic set of services which could be available to each child with a chronic condition. The need for a broad scope of services is clear. The emphasis on medical and surgical care,to the neglect of other services for families, can have a great detrimental impact on a child's development and functional ability. A child with spina bifida may have improved joint function after an orthopedic procedure, but lack of attention to her needs for physical and occupational therapy or to the barriers to her functioning better in school will diminish the quality of her outcome.

The scope of services will vary according to regional needs and capacities and according to the needs of individual families. Available services should include: high quality primary and specialized health services; educational planning; specialized nursing services, especially to provide families skills in home care; other support for the family's ability to carry out most care for their child at home; nutritional

services; and a wide variety of counseling services, to deal with issues of genetrics, finances, prognosis, and child development, as well as psychological counseling to strengthen families' abilities to cope with the additional stress created by a chronic illness in a child. Other services, such as physical and occupational therapy, will be needed by children with some conditions. Most families with chronically ill children will need only a very limited number of services from this list. Various levels of service should be available throughout a region, since only a few families require the most intensive, costly and comprehensive services.

Individualized Service Plans and Coordination of Care. Access to needed services will be best assured with the development of an individualized service plan for each child and family. The plan, developed in coordination with the family, should outline services to be provided to the family, including not only medical and surgical services, but also attention to education, family support, counseling, and the like. The plan should have clear and explicit allocation of responsibilities to providers or agencies for carrying out elements of the plan, and should allow for periodic monitoring and updating.

Each plan should define a specific person to be the coordinator of care for the child and family. Many different types of people can provide care coordination for a family, including family members themselves, social workers, lay counselors, physicians, school personnel, and others. Who provides the service is much less important than that the function of care coordination be carried out by someone.

Regionalization. An effective regionalized program includes activities and services in local communities, in the core regional coordinating staff, and in the specialty centers. The distinction between centralization and regionalization is a key one. A centralized focus emphasizes the development of high quality specialty services and the strengthening of the capacity to provide services of high quality at a central place. Centralization in the area of care for high risk newborns, as an example, would be the development of excellent intensive care nursery programs in academic health centers, without attention to strengthening services in smaller community hospitals, where most children are born. Regionalization of services requires the development of excellent specialty services, in the context of developing similar excellence at the community and coordinating levels as well.

At the community level, it is important to identify the health providers, especially physicians and nurses, who can provide excellent, ongoing primary care for chronically ill children. In addition, a mission of the regional group is to encourage the development of a new class of nonprofessional or semi-professional personnel, chronic illness generalists. The generalists will serve as resource finders in local communities, help to ensure communication among families, health providers and schools, and collaborate with regional colleagues. Local chronic illness generalists can also aid the development of groups of parents and children to provide mutual help and education. Such groups may include families with a variety of illnesses, especially in communities in which the numbers of children with individual illnesses are small.

A vital activity in local communities is the development of educational programs, to increase awareness of chronic illness in childhood and

improve the integration of children into the mainstream of community life. The generalists would provide information and consultation to community institutions involved with children, especially the schools. Community health providers, too, need continuing education in issues of chronic childhood illness, a process best provided close to the site of practice, perhaps under the sponsorship of regional staff.

At the regional level, there should be a core of professionals, knowledgeable about a broad range of issues related to chronic illness in childhood rather than specialists in specific diseases. Five main groups of skills should be available in the core group: pediatric, nursing, social work, mental health, and education. The regional group might consist of a pediatrician, a chronic illness nurse, a social worker, a psychologist, and a teacher, though in some locales, more than one discipline could be covered by a single individual. Professional staff may be supplemented with a number of non-professional colleagues, depending on the size of the region and the size of the affected population in the region.

The basic core group could be implemented within any of a number of existing structures as well as in new organizations. Existing structures include Title V agencies, certain school districts, academic health centers or university affiliated facilities, local or regional health departments, family service agencies, and some mental health centers. The structure is likely to vary from region to region and will depend upon the strengths of different agencies and their ability to coordinate a broad range of services for chronically ill children.

The core group would serve the region, with responsibilities to a) develop and monitor a data base, b) develop identification and referral systems

for children, c) implement systems of communication among levels of care, d) develop regional education programs, and e) assure the development and implementation of individualized service plans for children in the region.

a) Data should be gathered on a periodic basis to reflect needs, services, and resources. A regional data base should identify specialty care services and referral sources, pediatricians and other primary care providers for chronically ill children in all parts of the region, school resources, developmental programs, and other community agencies providing services to handicapped children. The data base should also provide information on the services provided, both medical and non-medical, to permit monitoring of the adequacy of the regional plan in meeting service goals.

b) An early identification and referral system for children with special needs is a second responsibility of the coordinating group. Since most chronic childhood illnesses are individually rare, primary providers should have easy access to information on identification of unusual problems as well as sources of specialty care. Identification and referral systems should also be available to school personnel since many chronic problems are identified by schools rather than in physicians' offices.

c) Communication among the various people involved with the care of chronically ill children is essential to the childrens' and families' well being. A task of a coordinating group is to assure adequate communication between primary and specialty health services, between providers and schools, and between families and their educational and health caretakers.

d) Regional education programs for school personnel, health providers, and the community at large should be organized by regional staff in coordination with the activities of personnel in the local community.

e) Development and periodic review of an individualized service plan for each family is the responsibility of the regional coordinating group.

The core group may provide some services directly, according to regional needs. Many coordinating services are carried out now by primary health care providers or by teachers or nurses in schools, and the expansion of this ability on the local level will be encouraged, with the regional group serving mainly to help in finding resources of a wide variety and in improving coordination and communication between the community and specialty levels.

The actual size of regions will vary according to community needs and resources. Regions should be small enough that the coordinating group can be knowledgeable about a broad array of services and large enough that most needed specialty services will be available. In all cases, regions would be smaller than a single state. Most states would have several regions, and in larger cities there may be several regions.

Eligibility. The proposed program recognizes a generic definition of chronic childhood illness: a health condition which leads to hospitalization for more than one month in a year, or interferes with the child's ability to carry out his usual daily tasks for more than three months in the year, or at the time of diagnosis is likely to do so (for example,leukemia and certain birth defects). Because childhood chronic illnesses are relatively rare and because there is need for very specialized and scarce resources, it makes little sense to develop chronic disease programs in the public sector separate from those in the private sector. To develop a public spina bifida clinic separate from a private one seems unnecessary duplication with unneeded extra cost. Therefore, the regionalized program should be available to all families with chronically ill children, regardless of their financial status.

Financing. Financial support for the national regionalized program for families with chronically ill children could take various forms. One option is for full public support, either Federal or by a combination of Federal and State revenues. Each regional program will likely need some core support to build and maintain the regional infrastructure. Such support could come in the form of a grant program from private or public sources. For most health services, support could come from a number of insurance mechanisms, including prepayment plans for chronically ill children, or from present third party payers, both public and private, for children. A child and family who become eligible for the program, by meeting the generic definition of chronic illness, would have access to the scope of services defined in the regional plan. The cost of most of these services would be borne by the original insurer. Additional public monies would still likely be needed in two further areas: to support some essential services not payable by present insurers and to finance insurance for the ten to twenty-five percent of families without third party coverage.

Summary. The special needs accompanying chronic illness in childhood are complex and are unlikely to be met by simple solutions. Family needs will be met best through the establishment of an effective regional program, emphasizing comprehensiveness of services, coordination, continuity, and communication. Attention to local communities, regional coordinating activities and specialty centers will enable families to support the growth of their children and to encourage their participation in the work-place of children, the school.

Issues and Recommendations for Change in Existing Policies and Programs

The health care system for chronically ill children and their families is defined broadly. The project identifies issues and problems and makes recommendations in the main areas of the system: organization and financing of medical and non-medical services, schools, research efforts and training programs. The project recognizes that there are paths to improved policies and programs for chronically ill children and their families with or without the adoption of the proposed Regionalized Program for Families with Chronically Ill Children. Modifications in the system of care may enable existing programs to meet more effectively the extraordinary needs of chronically ill children and their families. Recommended changes will also move the system of care and services in the direction of the recommended national program.

Issues: Organization of Services

- The specialization that has improved the medical outcomes for chronically ill children has resulted, ironically, in fragmentation of medical services. The lack of coordination of services, not normally a problem in the care of children with acute illnesses, takes on serious proportions when there is severe chronic illness.
- The diverse providers who treat an individual child infrequently coordinate their efforts. Caregivers may change over the long haul of the illness and its often complex treatment. Families often lack supportive counseling in the care and management of the child with chronic illness.

.Public programs such as those supported by the Crippled Children's Service, Medicaid and the federal research agencies, provide many essential services to chronically ill children. Yet they often favor the provision of high technology services (usually at high cost) and neglect relatively the broad base of services needed to maximize child functioning and family potential.

Recommendations: Organization of Services

Improved regional efforts can develop through any of a number of present structures, including state Crippled Children's agencies, the University-Affiliated Facilities (for children with developmental disabilities), or the disease-specific comprehensive care programs (such as those for children with hemophilia). The following recommendations have been implemented in part in several areas of the country. The Vanderbilt project sees them as key elements to incremental improvements in services for chronically ill children and their families.

.Regional data systems should be developed, broadly incorporating information on a) populations and children in need of services, b) services provided, and c) regional resources for chronically ill children. Data should reflect medical and surgical care along with other services including educational, genetic, psychological and nutritional care. Such data should lead to the development of regional plans for chronically ill children, permit identification of major gaps in services, and allow monitoring of the effects of program changes.

.The Scope of Services for each service agency should be explicitly defined and when taken together available services should be broad enough to meet the large variety of family needs resulting from chronic illness in a child.

.Individual Service Plans should be developed (and periodically monitored) for each chronically ill child. Plans should attend to main realms affected by chronic illness or otherwise important to the progress of the child, including medical-surgical, developmental, educational, and family. Although all services will rarely be carried out by any one provider, the plan should carefully allocate responsibilities for each service to a specific provider. Otherwise, a needed service may be omitted by several providers, each believing another is responsible for the service.

.Maintenance of the strengths of specialized care centers is essential to assuring quality technological services. These centers, usually in academic health centers, need protection from potentially negative impact of new competitive financing proposals.

.Greater responsibilities for primary providers in the care of chronically ill children should be encouraged. Primary providers are usually closer to families than are specialists both geographically and in the sense of knowing the families. Although some are reluctant to assume added responsibilities of working with families with chronically ill children, many provide excellent treatment, care coordination, and family support. The role of primary providers will be enhanced by a) more equitable reimbursement for time invested

in complex family and illness problems, b) effective continuing education, and c) improved regional communication systems emphasizing easy transfer of information among different providers.

Case coordination is critical to improving services for chronically ill children and their families. Coordination is a function which can be carried out by any of a number of people, including nurses, social workers, pediatricians, and lay counselors. That the function be carried out is far more important than who does it. Effective care coordination will improve the functional outcome for the child and family and may cut down on unnecessary utilization of expensive health services. The importance of care coordination should be recognized by reasonable reimbursement for the service.

Implementation of the recommendations to improve organization of services can come through a targeted project grant program to agencies. Eligible applicants could include academic health centers, state or local C.C.S. agencies, developmental disabilities programs (including UAF's) among others.

Issues: Costs and Financing of Services

Children with chronic conditions, particularly those with functional disabilities, require much greater than average use of hospital and ambulatory care. In 1977, chronic conditions accounted for 36 percent of total hospital days for all children less than age 15 in the United States. Similarly children limited in activity had greatly increased use of hospitals and visited the doctor more than twice as much as other chronically ill children.

.In 1980, expenditures for physician visits and hospitalization of children with activity limitation totaled over $1.6 billion; 65% of these costs were for hospitalization. Children with the most severe limitations have the highest per child costs as well -- three times the national average for all children.

.The cost of care of children with chronic illnesses is beyond the capability of most families. Small studies found, for example, that direct medical costs for children with hemophilia averaged $10,000 in 1980, and some cases cost well over $50,000. Direct medical costs for infants with congenital heart disease were $13,000 in the first year alone. Medical costs of children with cystic fibrosis ranged as high as $20,000. These figures include neither direct non-medical costs such as transportation and telephone, nor indirect costs such as lost salaries, opportunities foregone and diminished energies.

.Families with chronically ill children who receive SSI benefits report out-of-pocket costs as high as $1,500 per month.

.Public programs account for half of all expenditures for the care of chronically disabled children, including chronically ill children. Clearly the combined effect of simultaneous reductions in these programs -- Medicaid, Medicare and the Maternal and Child Health Block Grant (Crippled Children's Service) -- is very serious for chronically ill children.

.The distribution of payment for the medical care of chronically ill children is capricious. There is great variability of financial

coverage by income, condition, severity, type of services and geography. The gaps in coverage are of several types.

-Gaps in benefits. Many programs fail to reimburse for services used frequently by chronically ill children -- transportation, social services, home care materials, and genetic counseling.

-Gaps in populations covered. 10% of all children with functional limitations have no insurance, public or private, and 20% of low income children with functional limitations are uninsured.

-Gaps in public programs. Medicaid covers only 25 percent of the disabled child population and only about 60 percent of disabled children below poverty. State variation in Medicaid eligibility and scope of coverage for disabled children is tremendous. Only 10 percent of Nevada's chronically ill children are covered compared to the District of Columbia's coverage of 50 percent. This range is even greater among low-income disabled children -- 20 percent in Nevada versus 86 percent in New York. Crippled Children's Service programs serve over a million handicapped children, at a cost of nearly $300 million. Large variations exist between CCS programs in numbers of children served, generosity of state programs and conditions eligible for treatment. The Supplemental Security Income program, another important federal program for the disabled population, covers few children; only 5% of SSI beneficiaries are children.

-Gaps in private programs. The role of private voluntary health associations in financing care for disabled children is limited to "insurors of last resort." The associations vary not only in their size but also in their distributions of expenditures for research, medical services, professional education and training, public health education and community services and advocacy.

.Many of the nation's children are not covered by private insurance, and chronically ill children are almost twice as likely as other children to lack this coverage. While private insurance does not cover 25% of <u>all</u> children, it does not cover 40% of <u>disabled</u> children.

.Exclusion from private group insurance policies occurs in a number of circumstances: employment in small firms or on a seasonal basis, self-employment and unemployment; lack of conversion privileges to individual policies for many employees — for those whose jobs terminate, for spouses of divorced or deceased employees, and for employees' dependent children who marry or reach the age limit under group policies; and waiting periods for pre-existing conditions.

.Competition proposals are based on an assumption of little applicability to most chronically ill children and their families: that choice is a principal determinant in the use of medical services. But for chronically ill children, this is usually not the case.

Recommendations: Financing of Services

Most proposed changes in health care financing attempt to meet varying and sometimes competing policy goals: assuring that citizens have access to basic health care, assuring that ruinous cost is not incurred, and at the same time controlling the costs and expenditures in the health care sector. Principles to guide consideration of new financing proposals follow, with comments on important aspects of both proposed and current financing programs as they affect chronically ill children and their families. Policy should recognize that chronicity means a financial outlay year after year, not just for acute episodes which typify most childhood illnesses; the high cumulative expenses can ruin families financially. All families with severely chronically ill children require access to financing of a broad range of services, regardless of the parents' employment or economic status.

.Implications for private health insurance programs based on fee-for-service are:

-Access to the relatively broad and deep coverage of group policies is linked to employment, mainly in large firms. Some of the remedies for exclusion from group insurance policies that could benefit many chronically ill children and their families include extension of coverage to low-wage or seasonal employees, conversion privileges from group to individual policies, and mandatory coverage of dependents in family policies. Conversion privileges for dependent children would be especially helpful to chronically ill children who reach the age at which they are no longer covered by their parents' policies. Several states have mandated high risk pools, in which all insurers in a state share the risks for uninsurable persons; high risk pools can provide protection to chron-

ically ill children and their families although they entail high annual out-of-pocket expenditures for premiums, deductibles and co-insurance.

-Because most insurance plans are oriented to high-cost hospital inpatient care, they tend to cover only medical services or ones offered under the direction of a physician. They seldom contain incentives to preventive and primary care, nor do they cover the broad range of special services and materials — outpatient drugs, tests, and so on — that are essential for chronically ill children. Fee-for-service insurance systems need encouragement to provide coverage of a different mix of services, as some are now doing (e.g., recent experimentation with coverage of home care as an alternative to hospitalization). Coverage of ambulatory services, rehabilitation and health education would improve the care of chronically ill children and might prevent costly hospitalizations.

-Insurance through prepaid group practices rather than fee-for-service might provide a broader mix of services, contain aggregate health care costs, and protect families financially. Access to the highly specialized care needed by many chronically ill children needs to be assured in capitation programs.

.Implications for <u>catastrophic health insurance</u>, proposed in a number of forms in recent years as the preferred form of national health insurance, include:

-Catastrophic health insurance is criticized frequently for causing reallocation of health resources away from preventive care

to higher cost care, hospitalization, and other services that already receive disproportionate coverage. However, properly structured, catastrophic insurance could provide valuable protection to chronically ill children and their families.

-Catastrophic health insurance plans have tended to address the costs of a catastrophic event rather than solving the equally serious problem of expensive chronic illnesses. For example, most plans provide reimbursement only after 60 days of hospitalization in a year, a benefit that excludes the large number of chronically ill children whose days in the hospital may be fewer per year, but whose hospitalizations recur frequently. In addition, most of the proposed plans do not provide reimbursement for outpatient drugs, often necessary in large and costly quantities for chronically ill children. An alternative provision would be to apply all major medical expenses toward a single deductible amount.

-The enormous financial burden on families of children with chronic illnesses is not reflected in calculating only one year's expenses. The large expenses persist year after year. Most catastrophic insurance proposals are directed to cushioning a family against having savings wiped out by a single event. An alternative policy would be longer deductible periods, of perhaps several years.

-An income-based deductible which limits expenditures on medical care to 10-15% of income would be especially important for young adults with severe chronic illnesses. These young people fre-

BEST COPY AVAILABLE

quently are unable to retain full-time employment, yet they do not qualify for Medicaid. Income-related insurance protection would make a great difference in access to care and financial independence.

.Some implications for <u>competitive</u> proposals include:

-Most competition proposals are likely to cluster users of many services and therefore of high cost care in the higher cost plans. "Adverse selection" could price the higher benefit plans needed by chronically ill children out of their reach. Methods to share the risk need to be included in competition plans.

-Competition plans place limits on the percent of income or the flat dollar amount the individuals must pay out-of-pocket for health care before the insurance plan pays for care. However, the narrow definition of eligible services and their definition as related to a "spell of illness" means that many services used by chronically ill children are not counted in the deductible. To meet the needs of chronically ill children, the deductible should take into account all the out-of-pocket medical expenses and the price paid for insurance premiums, and be based on a reasonable percentage of income rather than a flat dollar amount.

-Competition approaches or the removal of tax exemptions for insurance premiums could result in more circumscribed plans.

In sum, these approaches must be designed very carefully so as not to isolate families with predictably high medical care costs, making it more difficult for them to find adequate coverage.

.Some implications for government funded programs:

-Medicaid has unquestionably made a significant contribution to the care of chronically ill children by financing hospital and outpatient benefits previously not available. The uneven pattern of eligibility and benefits among the states is exacerbated by the cuts in funding in recent years. Further such reductions will only harm further poor chronically ill children and their families. Cost containment through medicaid capitation plans, use of home-based care to substitute for hospitalization, and other administrative rearrangements are vastly preferable to reductions of eligibility and benefits.

-Crippled Children's programs finance a wide range of inpatient and outpatient services through various arrangements. Each state has a unique service profile and wide discretion in selecting the conditions to be treated. Maintaining the funding level of the CCS program within the Maternal and Child Health Block Grant is of great importance to chronically ill children, in light of the special services for these children the CCS provides. Modification of CCS in the direction of the proposed Regionalized Program for Chronically Ill Children and their Families would distribute CCS benefits more effectively and equitably.

Issues: Schools

.Education serves a number of important functions in all children's lives, and its significance for children who have special problems cannot be overestimated. Many chronically ill children evidence no unusual learning problems but many require medical and physical accommodations to participate in school. Under P.L. 94-142, they need "related services" without needing "special education"; yet by definition there can be no related services without special education.

.Chronically ill children may need specialized instruction (e.g., vocational and career preparation, or even adaptive physical education, nutrition, and care of appliances) in addition to instruction in traditional academic areas. These needs are considered by many teachers and administrators to be outside the purview of the public schools. Professional preparation programs for handling medical matters in the classroom are unavailable for the most part.

.Teachers' attitudes regarding expectations for academic achievement by chronically ill children often result in exaggerated deference to the medical implications of a child's handicap. The teacher, the parent, and the physician may have different and sometimes incompatible goals for a chronically ill child.

.Development of plans for children with special health needs is limited too often by calling for services that are available already in a school system rather than for services the child

actually needs. Costs to local education agencies, which have assumed the provider functions, are cited as a deterrent to provision of a broad range of health services that may be needed.

- A major educational problem of chronically ill children is frequent or occasional interruption in school attendance, from prolonged hospitalization, regular weekly treatments, or unpredictable three or four day absences. Current home and hospital school programs, often the only means of providing educational services to sick students, are characterized by great diversity in rules, requirements, and quality. Rigidity in absence requirements for eligibility for home programs and brief length of teacher time on a weekly basis (most states require only three hours per week) illustrate some of the problems.
- The need for supportive services in school complicates educational placement and programming decisions for chronically ill children. Service needs may include special diets (for students with asthma, diabetes, or advanced kidney disease), physical therapy and special transportation (for students with rheumatoid arthritis), special physical handling (for students with spina bifida or muscular dystrophy), social work and liaison services, counseling, and in-school administration of medicines and treatments such as catheterization.
- Schools have limited health services for all children, and few educational authorities have developed and implemented specific policies and program health standards for children with special needs.

.Chronically ill children in school have great need for emotional support and opportunities to experience normal peer relationships. Some of the obstacles to meeting these needs include:

-erratic attendance patterns

-maladaptive social behavior

-embarrassing side effects of specific diseases

-isolation due to equipment needs or geographic location.

Perhaps the most important obstacle is the unavailability of support for parents in coping with chronic illness.

Recommendations: Schools

.The chronically ill child whose condition only mildly or infrequently affects schooling -- children who occasionally require medications or who need modified gym classes — are most appropriately served by the regular education system, utilizing counseling and school health services. To insure that the chronically ill child with a mild impairment receives the necessary services within each school district, each state should adopt explicit school health codes for chronically ill children and mandate adoption by local school systems. Codes should include policies and procedures at least in the following areas: medication procedures, case registry, emergencies, in-service training, and case coordination.

.Special education, as defined in P.L. 94-142, should not be extended, or stretched, for the purpose of including nonhandicapped children who are in need of "related services." However, the related services portion of that law should be revised (or separated in law) to require the provision of related services to all children,

handicapped or not, if essential for children to participate effectively in an appropriate education program in the least restrictive environment.

- More flexible policies regarding the use of homebound and hospital instruction should be adopted. The consecutive absence period necessary currently to qualify for homebound services results in many chronically ill children going without important instructional services.
- Schools must adopt internal policies for coordinating regular education and special education. These educational entities should not remain separate service delivery systems with different technologies and goals. In the event related services are made available to children based upon need, the three sections must interact on a regular basis.
- Training within the school regarding chronically ill children, and efforts to educate and sensitize should be directed at both school personnel and other students. School personnel should receive training related to a child's specific condition under the direction of a school nurse or physician. Specific curricula or techniques to explore and modify student and teacher attitudes about chronically ill children should be developed. Supportive personal counseling may be required for school personnel involved with the education of children with terminal or progressive illness.
- Schools must have health related information about chronically ill children for proper placement and programming to occur. Appropriate functions for the physician are the transfer of information to the

schools and the fostering of two-way communication between schools and physicians. In general, the physician's role as a consultant rather than an educational decision-maker needs clarification.

Issues: Research

.The dramatic improvements in the treatment of many chronic illnesses in the past quarter century have in large part come as a result of a sizeable investment in basic biomedical research, mainly through the National Institutes of Health. Interinstitutional studies of childhood cancers, supported by the National Cancer Institute, as an example, have reversed the prospects for many children with leukemia and other previously uniformly fatal illnesses. Similar examples abound in such areas as chronic kidney diseases, the prevention of birth defects, and the treatment of cystic fibrosis.

.Many important advances have come through collaborative research among scientists representing different biomedical disciplines, for example, physiology and biochemistry.

.Support for basic biomedical research has plateaued in the past few years, diminishing the rapid growth in new knowledge characteristic of the previous two decades.

.Greater limitations on available funding have diminished the attractiveness of research careers to many potentially excellent young investigators, and the infusion of new talent to many areas of basic research has been sharply limited.

.Support for basic research in other disciplines critical to the needs of families with chronically ill children has been far less generous. Investment in behavioral sciences research represents a minimal percentage of the NIH effort in chronic illness. Even less support has been available in such areas as health services and nursing science research.

.For psychologists in academic health centers, as an example, it is rare that one can achieve research support, despite the pressing need to increase the understanding of basic mechanisms of psychological impact of chronic illness, the processes of coping, and the interaction of psychological matters and physiologic response to illness. Where groups of behavioral practitioners have become involved with chronic childhood illness, main support has been from direct service activities and not for the development of new knowledge.

.Careful and timely assessment of new technologies is critical to the care of children with chronic illnesses. Federal efforts in assessment have included the Office of Technology Assessment and the National Center for Health Care Technology, yet the former has paid little attention to the needs of children and the latter was dismantled not long after its creation.

.Several Federal agencies other than the NIH have variably supported research in chronic child illness, including the Office of Maternal and Child Health, the National Institute of Mental Health, and the National Center for Health Services Research and Development. These efforts have been curtailed markedly in recent years and agencies are somewhat adrift

in defining their research missions, especially as they relate to chronic childhood illness.

Recommendations: Research

.Support for basic biomedical research, via the mechanism of the NIH, should remain a very high priority.

.The investment in basic biomedical research should be balanced with an equally vigorous commitment to basic research in other critical areas, including behavioral sciences and health services research.

.A number of areas appear especially promising, for example, in primary prevention of handicapping conditions and in improving the process of childhood coping with chronic illness. Support for basic research in genetics, in the development of certain new technologies (such as the insulin pump for diabetes), in epidemiology, and in family coping and adjustment merit special attention.

.Several arguments mitigate against the study of illness only among patients appearing in teaching centers for tertiary care hospitals. Population-based studies of chronic childhood illness are essential to understanding the diseases, their onset, ramifications, and treatment.

.Given the relative infrequency of many chronic childhood illnesses, adequate numbers of children with any specific disease may not be found in a single center. Interinstitutional research should be fostered and supported.

.Successful collaboration among different biomedical disciplines should be expanded to stimulate joint research ventures among such disciplines as psychology and medicine, physiology and nutritional sciences, nurse-researchers and pediatrics.

- Support for the training of scientists, especially from the clinical disciplines, to develop strong quantitative and data management skills and incorporate the tremendous expanding knowledge in the field of clinical epidemiology, needs expansion.
- Much basic research in child development has come recently from the area of developmental disabilities, often with support from the National Institute of Child Health and Human Development. The skills and developmental knowledge arising from this research have major implications for chronic illnesses in childhood as well and should be creatively applied to this area.
- Recent efforts to clarify the ethical considerations in research on children are commendable and outline an area of fruitful future investigation. Though the balance between ethical pursuits of new knowledge and preservation of the rights of children may be difficult to achieve, inattention to the problem may lead to potentially dangerous and unproven therapies applied haphazardly to children.
- The benefits of research should find timely application in service programs for children and families. The development of regional, integrated programs for chronically ill children will improve the daily interaction between those doing basic research and those providing varied levels of service.

Issues: Training of Providers

.Most health providers, regardless of discipline, have limited experience with chronically ill children during training. Pediatricians, health professionals with perhaps the greatest direct experience with childhood illness, are mainly exposed to the acute exacerbations of chronic conditions and only occasionally to the long-term problems and family aspects of chronic childhood illness.

.Nursing training, especially with new integrated curricula, offers little opportunity to consider chronically ill children during undergraduate years. Even in specialized graduate nursing training, opportunities for long-term supervised interaction with families with chronically ill children are very limited. Other health professionals (e.g., psychologists, nutritionists) may have even less exposure.

.Physician training emphasizes acute treatment issues, rather than long-term and family management problems, partly because reimbursement is more available for treatment than for support services. Reform in physician training will likely accompany reform of payment for health services.

.Public health practitioners provide leadership of Crippled Children's and related programs. Yet their training is often divorced from the places where chronically ill children and their families seek health care. The separation of public health people from the clinical realm has led to some of the

fragmentation of services for children and diminished the likelihood of effective public-private collaboration in program development.

.Faculties of key professional schools (e.g., medicine, nursing, psychology, social work) rarely include members whose academic focus has been the broad problems affecting families with chronically ill children. Faculties may include many disease specialists, but rarely generalists interested in chronic childhood illness, its coordination or family implications.

.Physician training especially emphasizes curing rather than caring. Yet the very fact of chronicity means that most of these conditions last indefinitely without cure.

Recommendations: Training of Providers

.Increased attention to the problems of childhood chronic illness is needed in all health professional schools. Training should emphasize:

-longitudinal experience with the families of chronically ill children, during both acute and quiescent phases,

-collaboration among disciplines in working with families, and

-a broad definition and approach to child and family needs.

.Concepts in the care of children with chronic handicaps are applicable to several other realms, such as geriatrics or substance abuse. Special emphasis is needed in professional schools on concepts from clinical epidemiology, patterns of human adaptation, ethical decision making in long-term care and principles of patient management (distinguished from disease cure).

.Training in the family and developmental impact of chronic childhood illness is important for specialists and generalists alike. Trainees need skill not only in dealing with disease processes, but also a firm understanding of the influences of genetic, familial, environmental, and social factors on chronic illness in children.

.Basic understanding of nutritional concepts, psychological precepts and educational issues (both to promote healthier behavior and to work effectively with schools) are essential for the training of involved health professionals.

.A few exemplary training programs in chronic childhood illness should be developed. These should be interdisciplinary in faculty and in trainees and should have the goals of producing both new researchers in the broad area of chronic childhood illness and other graduates able to provide leadership to public programs for children with handicaps. Unlike most present programs housed in schools of public health, the new training programs will be based within academic health centers, probably in the context of organized regional programs for families with chronically ill children.

.Faculties of nursing, medicine, and related fields should expand attention to the generic problems of chronically ill children by adding new members expert in these problems, likely graduates of the training programs above.

.Training for research careers, both in disease-specific areas and in chronic illness in general, remains a high priority. There is con-

tinuing and indeed increasing need for researchers well-grounded in quantitative skills and methodologic principles, and with good backgrounds in theory applicable to the problems of sick children. Yet opportunities for research training in chronic illnesses of childhood, outside of specialty fellowships for pediatricians, are limited, especially in nursing and psychology. New interdisciplinary training programs will fill an important gap.

.Continuing education for child health providers should address issues in early identification and referral of chronically ill children, new developments in management of chronic illnesses, aspects of care coordination, and advances in understanding of family coping and adaptation.